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Focus Group Results from the National Evaluation of *Medicare & You* 2000 Handbook: Beneficiaries

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TABLE OF CONTENTS

	Page
List of Tables	ii
Executive Summary	iii
1.0 Background and Introduction	1
2.0 Methods.....	3
3.0 Description of Groups.....	6
3.1 Participation.....	6
3.2 Beneficiary Characteristics	6
3.3 Group Dynamics	9
4.0 Results.....	11
4.1 Access	11
4.2 Awareness.....	14
4.2.1 Purpose.....	14
4.2.2 “Original Medicare”	15
4.2.3 Services/Resources	16
4.3 Understanding.....	17
4.3.1 Self-Rated Knowledge.....	18
4.3.2 Other Information Sources.....	19
4.3.3 What Is Difficult to Understand.....	21
4.3.4 Medicare HMOs.....	22
4.3.5 Coverage for Long-Term Care.....	25
4.3.6 Quality of Care Information.....	26
4.4 Impact and Use	29
5.0 Conclusions and Policy Implications.....	32
Appendix A: Final Medicare and You Beneficiary Focus Group Topic Guide	
Appendix B: Screening Guidelines	

LIST OF TABLES

	Page
1 Summary of Beneficiary Demographics by Site	8
2 Summary of Findings.....	33
3 Beneficiaries' Suggestions for the Handbook.....	36

Executive Summary

This report summarizes the findings from three focus groups with Medicare beneficiaries. The overall aim of this work was to contribute to efforts to evaluate the National Medicare Education Program (NMEP) by augmenting information collected in the national *Medicare and You* evaluation survey that RTI conducted between July 1999 and February 2000.

Most focus group participants remembered receiving a version of the handbook in the past, and they were generally proficient at navigating the handbook to find information. Beneficiaries generally perceived that the purpose of the handbook was to provide general knowledge and information about the Medicare program. The handbook also increased participants' awareness of HCFA-sponsored information sources, although many were reluctant to use the internet. Gains in participants' understanding appeared to be associated with the perceived relevance of the issues addressed. This was particularly apparent in discussions regarding managed care, with HMO members paying more attention to these materials than their fee-for-service counterparts. These findings suggest that it will be challenging to develop effective methods to assess the impact of the NMEP on beneficiary knowledge, as interest is an important intervening variable between exposure and gains in knowledge. Most participants saw the handbook as a reference guide.

1.0 BACKGROUND AND INTRODUCTION

This report presents the findings from three focus groups with Medicare beneficiaries conducted in April and May of 2000. The overall aim of the focus group activity was to contribute to efforts to evaluate the National Medicare Education Program (NMEP) by illuminating survey findings and suggesting directions for future evaluation initiatives.

Recent changes to the Medicare program increase the number and range of choices available to beneficiaries. The need for easily understood information about Medicare in a form that beneficiaries are motivated to use is greater than ever. The NMEP is HCFA's program aimed at meeting that need through a coordinated program of developing useful informational materials, making them available to beneficiaries, and motivating beneficiaries to draw on these resources in considering their Medicare options.

The goals of the NMEP are:

1. Increasing beneficiary **access** to information;
2. Raising beneficiary **awareness** of the new information resources;
3. Helping beneficiaries **understand** the choices available to them; and
4. Helping beneficiaries **use** the information to make an informed choice.

The research objectives for this focus group effort parallel the four NMEP goals.

The objectives were as follows:

1. Discuss beneficiaries' access to *Medicare & You* and other information sources.
2. Explore beneficiaries' awareness of the purpose of the handbook, the meaning of Original Medicare, and the services available to aid in decision-making.
3. Illuminate barriers to beneficiaries' understanding of Medicare, Medicare HMOs, coverage for long-term care, and quality indicators.
4. Learn how beneficiaries used the handbook, and what aspects they found most useful.

Section 2 of this report outlines the methods that were used in designing, conducting and analyzing the focus groups, while Section 3 offers a description of the groups and participants. The focus group findings are presented in Section 4, organized along the conceptual framework of the NMEP: access, awareness, understanding and use. In Section 5 we offer a summary and conclusions.

2.0 METHODS

Focus groups took place over a four-week period from late-April to mid-May 2000. The purpose of the focus groups was to augment the information collected in the national *Medicare & You* evaluation survey that RTI conducted between July 1999 and February 2000. The general topic areas were developed to meet the research objectives outlined above. The topic guide is included in Appendix A.

One focus group was conducted in each of three locations: Boston, Memphis, and Denver. These locations were chosen to represent varying different levels markets with different levels of managed care experience; we expected participants in the three regions to have different experiences and expectations. All three metropolitan regions contain at least 100,000 beneficiaries, and are differentiated by Medicare managed care penetration rates. Memphis has less than a 1% Medicare HMO penetration rate, Boston has 26%, and Denver has 49% of Medicare beneficiaries as members of HMOs¹.

The groups were conducted at the offices of local recruiting firms hired by RTI. The names and recruitment protocol for each firm are shown in Appendix B.

The focus groups varied in size from 8 to 11 participants. All participants were sent a copy of the *Medicare & You* 2000 handbook by Federal Express two to five days prior to the session. The relatively short interval between receipt of the handbook and the

¹ "Medicare Enrollment by State and County of Beneficiary Residence" updated July 8, 1999 (<http://www.bcfa.gov/stats/cnty98en.pdf>).

date of the focus group was intended to minimize the potential for participants losing or forgetting the handbooks. This short interval, along with an enclosed letter reminding the participants to bring the handbook to the meeting, had the additional unintended consequence of giving participants the impression that the handbook was the subject of the interview. Participants in all three beneficiary focus groups demonstrated a tendency to return to the handbook even when asked to discuss overall perceptions and concerns regarding the Medicare program in general.

Using the topic guide, a trained moderator guided participants through a discussion on the predetermined set of topics and encouraged them to express their opinions and experiences. A co-moderator was also present to observe and record notes on verbal and non-verbal exchanges. The sessions were videotaped. Each group lasted about 2 hours, and after the interview each Memphis participant received a \$40 cash incentive, while each Boston and Denver participant received \$50 as a token of appreciation for their participation.² Following each focus group, the moderator and co-moderator debriefed prior to completing a debriefing form to document main themes and illustrative participant quotes. These debriefing forms, as well as the notes collected by the moderator and co-moderator during the interviews, were analyzed for common themes and differences among the groups.

Unlike a sample survey, focus groups cannot be generalized to a larger population. In addition, group dynamics of any one group can produce a bias, since some people may speak less because of others or a group may be swayed by the opinions of

²Payment amounts varied due to different costs of living and prevailing norms in the three communities.

one or two strong participants. At the same time, focus groups are a rich data source through which we can obtain in-depth findings that may help explain or enhance the findings from the quantitative data analyses. While we cannot generalize the focus group results, our confidence in focus group findings increases to the extent that patterns emerge regardless of group dynamics or location. The same moderator presided over all three groups, so variations by moderator are not an issue.

3.0 DESCRIPTION OF GROUPS

3.1 Participation

All eleven recruited beneficiaries attended the focus group discussion in Memphis, ten of the twelve beneficiaries recruited in Boston participated, and eight of the nine recruited beneficiaries in Denver were in attendance. The low no-show rate suggested the enthusiasm for participating in the focus group discussion among Medicare beneficiaries was strong. While some participants had been a part of other focus groups, no one had been previously involved in a health-related focus group.

3.2 Beneficiary Characteristics

We achieved a well balanced distribution of several demographic characteristics, primarily gender, age, and educational attainment, in the three focus groups (see Table 1). In contrast, racial and ethnic diversity in the focus groups was the primary demographic characteristic that was lacking. The demographic distributions observed in the various focus groups may be a reflection of the limitations in the recruiting firms' databases used to select the participants. The characteristics of the focus group participants are also likely to reflect the general demographics in the cities where the focus groups were conducted.

Racial demographics among the three cities vary significantly. Less than five percent of the Denver and Boston populations are African American.³ In contrast, nearly 35% of the population in Memphis is African American. While these distributions are not stratified by age, they do provide a general indication of the racial and ethnic make-up of the cities utilized for the data collection.

Gender patterns were similar among the three focus groups, however, the average age of the participants in the groups varied by site. Both men and women attended the focus group discussions, with more women represented in the Boston site and more men represented in Memphis and Denver. Denver's beneficiaries were consistently older, averaging 74 years of age, compared to Memphis (68 years of age) and Boston (70 years of age).

Consistent with the city demographics reported by *USAdata*, a pattern of regional differences in educational attainment existed between the three sites. This pattern was reflected in the focus group distributions. All of the participants in Denver, except one, had at least some college experience.⁴ In Memphis, however, approximately half of the individuals had some college experience, while the other half had earned a high school diploma.

³http://www.usadata.com/free_demographics.htm Scarborough, a local market research company (www.scarborough.com), measures 64 markets (including the top 50) via telephone interviews conducted through CATI and mail follow-up surveys among randomly selected adults 18 years of age or older.

⁴The exception was one woman who had a high school diploma. The individual who did not show up to the discussion also had a high school diploma.

While a relative mix of gender, age, and educational attainment was achieved in the three focus groups, representation from a variety of racial and ethnic groups was not achieved. The racial demographics of the city of Memphis were reflected in the focus group where three of the eleven participants were African American. Hispanic communities were not well represented in any of the three focus groups. Both Boston and Denver focus groups were entirely Caucasian.

Table 1: Summary of Beneficiary Demographics by Site

	Boston (n = 10)	Memphis (n = 11)	Denver (n = 8)
% White	100%	72.7%	100%
% Female	60%	45.5%	37.5%
Age			
Mean age (years)	70	67.9	73.5
>70 years of age	60%	18.2%	60%
Education			
High school graduate	50%	54.5%	12.5%
Some college	10%	27.3%	62.5%
College graduate	40%	18.2%	25%

A diversity in health care plan membership was a necessary characteristic for the focus group composition in order to accurately assess Medicare members' priorities, interests, and perspectives that may motivate their health care decisions. Medicare managed care members provided a unique set of interests and perspectives that were distinct from the beneficiaries who chose to be covered by Original Medicare. The extent to which managed care organizations had penetrated the health care markets in the three cities was reflected by the number of Medicare managed care members in the focus

groups. Six of the ten participants in the Boston group were a part of an HMO. The other four individuals had Medicare supplemental insurance in addition to Original Medicare. In contrast, no one in the Memphis beneficiary group was a member of an HMO. All Memphis beneficiaries had Original Medicare and some kind of supplement (employer-sponsored or individually purchased). With the Denver health care market having the highest penetration rate among the three cities, it was not surprising that all eight participants had joined an HMO.

3.3 Group Dynamics

The dynamics of focus groups are influenced in part by the individual personalities of those present. In general, the groups did not require significant facilitation from the moderator to carry the conversation. Participants were engaged, interested, and generally talkative. However, a dominant individual was somewhat disruptive to the conversational equilibrium in both the Denver and the Memphis groups.

A few challenges were encountered while facilitating the focus groups. First, quite a few questions were asked directly to the moderators about Medicare. This may indicate the perceived complexity of the Medicare program, or it may suggest that beneficiaries desire more information than they are currently able to ascertain. In these situations, the moderators made it clear that purpose of the focus group was to learn from the beneficiaries, and that moderators were not able to answer questions about Medicare.

Second, some participants wanted to provide contextual enrichment for their responses to questions based on their own health care experiences. Although this may be a result of the beneficiaries' desire to share their experiences and indulge an affinity for story-telling, it also suggests that to many people, issues of health coverage are inextricably linked to issues of health and health care. The personal stories provided the context within which the beneficiaries could understand the Medicare system.

4.0 RESULTS

This section presents the findings from the beneficiary focus groups, arranged along the NMEP conceptual framework of access, awareness, understanding and use.

4.1 Access

We explored issues of access in the focus groups, including whether participants recalled receiving the handbook in the autumn 1999 mailout, and what might help people to remember and pay attention to it.

In response to a similar line of questioning in the national survey, slightly more than half of those in the group of respondents who did not receive a remailed copy of the handbook reported recently seeing a copy of the handbook. About one-fourth of this group reported never really looking at the handbook, half read parts of it, while one-fourth reported most or all of it. Most survey respondents said the information in the handbook was at least “somewhat useful” for them, and 90% of those who were looking for specific information were able to find it.

In the focus group interviews we were interested in determining how much people are interested in the material found in the handbook, and whether they were intimidated by either the materials or the complexity of the Medicare program itself. We also hoped to gain insight into the linkage between how beneficiaries perceive the handbook and how they remember and use it.

We found that, as in the national survey, focus group participants in all three cities were generally proficient at navigating the handbook to collect information. During the discussions, participants frequently looked up the topics being discussed in the handbook to answer each others' questions. They were unlikely to have read the entire handbook. Those who did read the entire handbook were likely to have done so for the purposes of the focus group and could rarely remember material that didn't apply to them directly. One Memphis man said that he had read the whole thing for the focus group, but *"when I got it this fall, I read the parts that apply to me. I didn't need to read about HMOs."* A Denver man said that the handbook was *"like any other book, until you come down with a health problem, there is no way that you put importance on it. You're not going to go into depth. It's hard to do unless you have health problems."*

The response that while focus group participants felt healthy they weren't going to spend time reading up on Medicare was a very common one. One Boston woman remarked *"I did read it, but then it got almost boring...it just wasn't interesting reading material – especially with me feeling healthy and paying my premium."* A Denver woman referred to the handbook as *"voluminous,"* and thought she would most likely simply *"save it for her records."* Her perspective was that she had been lucky; *"I've had so little medical attention I put it aside as a reference. I don't need it because I have been so well."*

In most cases, participants considered the handbook a reference tool, and used it to answer specific questions as needed. This perception was fueled in part by the size of the handbook; the amount of information in it appeared to intimidate many participants,

as one Boston woman noted *"It covers a lot, you can't remember it all."* Another Memphis woman remarked *"To read the entire booklet and try to understand each revision, it's too much. The index helped me. I picked topics that concerned me. But to read all of this and remember how to apply it when I need it is a bit much."* A Boston woman said she had tried to read the handbook *"because I knew I was coming here. I had a lot of problems with the way it was written. I would hate for you to give me a test on it because I would flunk out. If you have a specific question it's good."*

As with the national survey, about half of the Boston participants remembered receiving a version of the handbook in the past. However, all but one participant in both the Memphis and Denver groups remembered doing so. Perhaps not coincidentally, while none of the Boston group recalled seeing any public service announcements (PSAs) regarding the handbook, several participants in the other groups remembered seeing notices in the paper or recalled receiving an informational letter from HCFA.

When asked what might help ensure that beneficiaries pay attention to future mailings, the vast majority of responses focused on ways to highlight the importance of the handbook as a reference tool. Ideas such as increasing the size of the date (to show this is a current informational source), a sticker saying *"save this in your files,"* and even charging a dollar for it were mentioned. A few participants pointed out that they are constantly receiving *"promotional stuff"* and that the handbook and the supporting letter enclosed with it were the most effective communication devices.

Overall, the vast majority of participants in our focus groups, as well as respondents in the survey, affirmed that they stored the handbook for use as a reference if and when they encounter health problems. While there appears to be an association between seeing PSAs regarding the handbook and remembering receiving it, most participants felt HCFA could ensure the handbook received attention by highlighting its role as a reference tool.

4.2 Awareness

RTI explored three aspects of beneficiary awareness in the focus groups:

- Perceptions of the purpose of the handbook
- The term “Original Medicare” and
- Awareness of the services available to Medicare beneficiaries to assist with understanding and comparing choices.

4.2.1 Purpose

In all three locations, beneficiaries generally agreed that the purpose of the handbook was to provide general knowledge and information about the Medicare program. Opinions varied as to whether it was intended to provide general introductory information (“*to inform you*,” as one participant said) or to be a reference tool (“*a dictionary to your health [care]*,” as was mentioned in Memphis), a source for seeking specific information on an as-needed basis. Perception of purpose seemed to be shaped by intended use; that is, in discussing the purpose of the handbook, people focused more on their own plans for how they would use it than on some objective notion of the

purpose of such handbook. This is exemplified in the comments from one Boston participant, who believed its purpose to be *“to answer specific questions I might have. I’m not interested in general knowledge – just what I need to know to deal with my and my husband’s problems.”* None of the focus group participants discussed the handbook in the context of the larger National Medicare Education Program.

Overall, participants believed that the handbook achieved its purpose, providing information, sources, and assurances for the parts of the Medicare program they didn’t understand and for questions that might arise. As one participant summed it up: *“It covers a lot of information – it points you where you need to go.”* This suggests that participants don’t perceive the purpose of the handbook to provide the definitive answers to all possible Medicare issues, but rather to point the way to sources for more detailed information.

4.2.2 “Original Medicare”

The term “The Original Medicare Plan” is used throughout the handbook. It is defined on page 11 of the handbook as follows: “The Original Medicare Plan is also known as ‘fee-for-service,’” and explained in more detail on subsequent pages. In fielding the survey, RTI became aware that some respondents were having difficulty understanding the term as it was used in the survey. To assess the impact this may have had on the survey findings, we explored participants’ interpretations of the term in the focus groups.

Responses differed by region. In the Memphis focus group, where all participants had original Medicare and none were members of Medicare managed care plans, there was general understanding: *“I thought it just meant the Original Medicare is what I have, and if I want another Medicare, it is an HMO or managed care.”* However, in both Denver and Boston, with higher Medicare managed care penetration, participants seemed a little more confused about the term, believing it referred to Medicare *“before we got all the changes,”* or *“before they added or subtracted to it later on.”* As one pointed out, *“You don’t have a comparison: original as opposed to what?”* It raised the question of whether what was offered now was original Medicare or something else.

The focus groups discussed what other terms might convey the same idea; while several participants favored “basic Medicare” (*“‘basic’ makes more sense”*), one noted that *“basic makes you wonder that you’re not getting very much, you’re getting the bare bones.”* *“Just call it plain Medicare,”* several participants recommended.

4.2.3 Services/Resources

Participants in all three locations were familiar with a variety of resources to aid in decision-making, offering examples like information from senior centers, Elder Services, Council on Aging materials, marketing materials, other people, unions, and former employers (for those with retiree coverage). The issue of marketing materials will be discussed in greater detail in the following section; in general participants seemed fairly savvy about them, and approached them with a healthy skepticism.

The handbook seems to have heightened participants' awareness of some of the HCFA-sponsored resources like the toll-free information line, the website and State Health Insurance Assistance Programs, though none of the focus group participants had availed themselves of these services. There was general reluctance to use the internet for this purpose, it would require possession of or access to a computer, which most participants did not have. (Though computers are available in many libraries and senior centers, it was clear that the majority of focus group participants did not feel comfortable with them.) More generally, participants expressed a preference for interpersonal interaction: "*I would rather talk to a person than all that information.*" They noted that counselors' and information providers' interpersonal skills differed ("*some are more caring and have more time*"), while still expressing a preference for one-to-one contact. "*I don't want nothing on tape; I want to talk to an individual.*" In general, participants said they would first rely on the handbook, and would turn to other information sources with specific questions or issues that were not fully addressed in *Medicare & You*.

4.3 Understanding

One of the aims of the NMEP is to increase beneficiaries' understanding of Medicare and their Medicare choices. The national survey found that while receiving the handbook did have a significant effect on beneficiaries' knowledge of Medicare + Choice issues, serious gaps in knowledge remain in some areas. In the focus groups, we set out to explore some of the dynamics surrounding knowledge and understanding, addressing such issues as:

- Self-rated knowledge
- Familiarity with other information sources
- The most difficult-to-understand aspects of the Medicare program
- Medicare HMOs
- Coverage for long-term care
- Quality indicators.

4.3.1 Self-Rated Knowledge

In the survey, we asked respondents “How much do you think you know about the Medicare program?” Responses were phrased in terms of need to know, e.g., “some of what you need to know.” This construction was predicated on a presumption that self-rated knowledge is a function of need to know. We chose to explore this as an open-ended issue in focus groups, allowing us to separate desire to know from need to know.

In effect, this line of inquiry supported the supposition that self-rated knowledge is shaped by participants’ perceived need for information. Across all three groups there was some variation in self-rated knowledge, with some participants saying they knew “*nothing*” or “*not a hell of a lot*,” while others felt more comfortable with their knowledge, saying things like “*I’m not an expert but I understand it*” and “*I pretty much have the information I need*.” The tenor of responses suggested that participants do assess their own knowledge relative to what they believe they need to know, rather than relative to what they’d like to know, or relative to some objective amount of information they should know.

We explored with focus group participants how much they thought they needed to know about the Medicare program. Here again responses reflected each individual

participant's perspective and interests. *"Don't you think people approach it as they need it?"* asked a Denver participant. The topic most participants agreed they needed to know about had to do with coverage: what is covered, by whom (Medicare or supplement), and at what level.

There was some regional variation on this issue. In Memphis, participants discussed needing to know about what was covered by Medicare Part B, by supplemental insurance, and by other sources (such as the VA). In Denver and Boston, with greater HMO participation, discussions had more to do with needing to understand the cost and coverage differences between fee-for-service Medicare and Medicare managed care. *"I had to know what problems I was having, and that was cost, and that's why I switched. You need to know enough about what you have to make the choice."*

These comments, taken together, suggest that participants' greatest need is for information about the costs and coverages associated with their Medicare choices (choices that may extend beyond the borders of the Medicare program, as with supplements, retiree coverage or VA benefits).

4.3.2 Other Information Sources

One challenge in assessing the impact of the NMEP on beneficiaries' understanding is teasing out the effects of any other informational materials to which beneficiaries have been exposed. We explored participants' use and assessment of other sources of information about Medicare in the focus groups.

Other sources of information about Medicare that participants mentioned included AARP, the news media, experience (often trial and error), friends and family members familiar with the health care system, and, for Boston and Denver participants, Medicare managed care organizations.

In Memphis, AARP was the most frequently mentioned source of information. *“AARP explains it in more detail... I don’t know that it is more accurate, but it has more details, it gives some examples... It explains so you can understand it.”* Participants found AARP to be an unbiased source of information, and they trusted it.

In Boston and Denver, there was more exposure to informational materials from Medicare HMOs and other sources. Participants found the HMO materials *“easy to follow and understand – they looked at it from the point of view of the consumer.”* In Denver, there was a lively discussion of the accuracy and trustworthiness of materials. Health plan materials were seen as more accurate (perhaps because they are more detailed), while most participants saw the HCFA materials as more unbiased. When asked if they would want both sources of information, the Denver group replied *“I think you have to.”*

Overall, participants’ understanding of the Medicare program and their options within it are shaped by NMEP as well as information from advocacy and proprietary organizations. Beneficiaries are able to distinguish between sources of information, and seem to attach different attributes to different sources, with AARP seen as member-

focussed, HMOs as consumer-oriented and detailed, and HCFA as trustworthy and unbiased.

4.3.3 What Is Difficult to Understand

In order to better understand participant gains in knowledge through the NMEP, the focus groups explored which aspects of the Medicare program are hardest to understand.

Responses varied across locations. In Boston, the only specific issue mentioned was Medigap: *“I think there is such a variety there, and it’s so expensive, so many contingencies.”* This participant went on to note that *“the handbook gave me a beginning – I would have to pursue choices in more detail.”* No other issues were raised in Boston, suggesting that perhaps participants weren’t familiar enough with the Medicare program to be able to highlight particular aspects they found difficult to understand.

In Memphis, participants found issues of coverage most difficult to understand. Issues included whether annual physical exams are covered by Medicare (and why they should be), referral to specialists, benefits for hospital stays, and coordination of coverage between Medicare and supplemental insurance providers. Participants did find the *Medicare & You* handbook to be useful in helping them to understand some of these issues better. However, some issues are too complex to be explained in the handbook. For example: *“I can never understand the price charged by the doctor and what is approved by Medicare. Either the doctor is pricing a hell of a lot too much or Medicare*

is shortchanging the doctor.” This highlights an area of understanding that goes beyond the borders of the Medicare program. Similarly, the complexity of billing for inpatient care was raised, highlighting the perceived need for coordination (again going beyond the boundaries of Medicare).

In Denver, *“financial stuff”* was the first issue offered as difficult to understand. This led into a discussion of the difficulty in presenting information about both the original Medicare Plan and Medicare HMOs – participants suggested that *“two books, with and without HMO”* might make that more clear.

Overall, we saw varied ability to identify what was difficult to understand. This may be a function of what individual beneficiaries are interested in, or what issues they have actually explored in enough detail to encounter difficulties. Several did find the handbook to be a useful resource in addressing the difficult issues.

4.3.4 Medicare HMOs

The survey results indicated relatively modest gains in knowledge about Medicare HMOs after receipt of the handbook. We explored participants’ understanding of HMOs in the focus groups, with an aim of understanding whether those modest gains could be attributed to lack of interest, lack of comprehension, the complexity of the program, or some other dynamic.

Here again we found notable regional variations. In Memphis, an area with low managed care penetration and no Medicare HMO members in the focus group, the group said they knew little about managed care and were not interested in learning more. They held definite notions that HMOs constrain consumer choice: *“You can’t go to the doctor you want to.” “HMOs make you leave the hospital when doctors don’t want you to.” “It’s more difficult to get appointments, too.”* These opinions were based on anecdotal reports from family, friends and the media, and the handbook did not appear to have provided additional (or countervailing) evidence. In this case, lack of interest and lack of knowledge seemed to go hand in hand.

In the Boston group, where some participants were HMO members, there was a wider range of views. In general, people who were not in Medicare HMOs did not know a great deal about Medicare managed care, and were not interested in obtaining more information. *“I’m not interested. I choose not to learn more.”* For participants like this, the handbook again had little impact on their knowledge or interest, as they paid little attention to the relevant portions.

Boston HMO members offered a different perspective. While they paid greater attention to the parts of the handbook addressing Medicare managed care than their fee-for-service peers did, they still had several questions that they did not believe were addressed in the handbook. Questions included why some providers were not associated with Medicare HMOs, and whether they were still in the Medicare program as HMO members. Early in the discussion an HMO member announced, with some dramatic flair, *“I turned in my Medicare card – now I have [a particular HMO].”* Later, when probed

as to whether Medicare HMO members are still in the Medicare program, this same participant responded *“Yes. I still pay Part B. It’s a government sponsored program.”* Noting that her HMO offered very generous benefits, she acknowledged that it might not be able to continue doing business. *“If they go under, I’ll have the government find me another one.”* Not all Boston Medicare HMO members shared that perspective, however, and there was also some confusion over the financial relationship between Medicare and the HMOs. Another HMO member said *“I’m of the understanding that [my HMO] is picking up the billing part of Medicare, and Medicare is paying them to do that.”* When probed as to whether Medicare pays for their care in the HMO, Medicare HMO members replied *“That’s not in the book.” “I couldn’t find that out. Somebody told me – nobody came out and said yeah, that’s true.”* These Medicare HMO members had reviewed the handbook for the information germane to their particular circumstances, but their understanding remained limited.

In Denver, where all focus group participants were HMO members, the discussion focussed on whether Medicare managed care participants were still in the Medicare program. While several participants said yes, a vocal minority disagreed: *“Medicare is for Medicare – I’m part of an HMO.”* In the ensuing discussion, another participant noted *“If Medicare didn’t pay the HMO, you’d be out of luck.”* As in Boston, the financial arrangements between Medicare and the managed care providers remained a bit murky, and participants seemed to rely more on individual experience and anecdotal information than on the handbook to further their understanding.

These findings suggest that people who are not in Medicare HMOs were not interested in the material and did not learn about managed care from the handbook. People with managed care did pay greater attention to the materials, but their ability to glean much new information from the handbook was limited.

4.3.5 Coverage for Long-Term Care

Because Medicare coverage for long-term care is limited, and long-term care is an issue for many older adults, we used the focus groups to explore beneficiaries' understanding of long-term care issues.

In all three groups, participants agreed that Medicare covers very little long-term care. In this discussion, participants were able to rely on the handbook, finding the relevant sections and reading them aloud to make their points. Here again they illustrated the usefulness of the handbook as reference tool, while reinforcing the notion that significant gains in knowledge in this area ought not to be expected. *"As long as they have this booklet, that's all they need. Will I remember this? No chance I'll remember this."*

While some participants thought it would be helpful to have more information on long-term care coverage, several offered opinions like this one: *"Most people don't even want to think about it unless they have a problem, or an illness that's going to require it."* This suggests that messages about long-term care may not be heeded by those who believe it not to be relevant to them.

Participants relied on other sources of information to learn about long-term care coverage, including senior centers, family members, and insurance agents. When we probed to ascertain if participants learned anything new about long-term care from the handbook, one beneficiary said *“there is very minimal coverage in this book on long-term care. It should be covered in more depth. Maybe it’s because they don’t cover it. I think they’re minimizing that.”* This group expressed interest in learning more about the different levels of care (e.g., retirement homes, assisted living, nursing homes, etc.).

Overall, participants were knowledgeable about Medicare coverage for long-term care, though interest in the subject varied according to the perceived relevance of the issue. Some of participants’ interests in the area extended beyond the boundaries of the Medicare program.

4.3.6 Quality of Care Information

The national survey found that people reported that they did not use the quality information in the *Medicare & You* handbook very much. We chose to use the focus groups as a forum to explore whether this is because respondents are not interested in quality, or did not perceive the indicators in the handbook as measures of quality, or did not see the indicators as germane to them.

There was general interest in all three groups in learning more about the quality of care associated with the various Medicare options. However, it was clear that participants had different notions of what was important in assessing quality.

“Everybody’s idea of quality of care is different.” “It’s an individual thing – what matters to me may not matter to others.” In discussing quality, most participants spoke in terms of the qualifications or attributes of their doctors, rather than quality of a health plan or the Medicare program. While some participants in each group tended to have their own notions about how to compare providers, a few also noted the pitfalls of this approach: *“If you get cured right away, you think you got quality care – maybe it was the doctor or maybe they were lucky.”*

We asked participants what the information in the handbook about how doctors communicate with patients told them. Opinions varied. In Denver and Boston, participants raised questions about the source of the information: *“I don’t know on what basis they were done. There are so many factors to quality – not just a bar graph.”* This exchange among three participants in Denver illustrates the variation in understanding:

- *“How could you measure that? Unless you stand outside the door.”*
- *“Send a questionnaire to 1000 Kaiser or Secure patients.”*
- *“That’s exactly what they do.”*

Participants in Memphis and Denver suggested that communication skills were less useful indicators of quality than clinical skills. *“I’m not concerned about being courteous, I’m concerned about competency. I’m not there for him to be nice.” “That’s communicating skills, that doesn’t say anything about medical skills.”* The latter remark drew this response from another participant: *“Oh, I like communication because I’m so dumb, I don’t know anything.”* This exchange illustrates the range of expectations and understandings people bring to interpreting this information.

We also asked about how participants interpreted the information in the handbook about how often women receive mammograms. While participants in all three groups agreed that this was important information, they did not necessarily see it as an indicator of quality. Some suggested that merely receiving the test was insufficient: *“I don’t see what this has to do with quality. They may get lousy mammograms.” “It’s not whether you get the screening – it’s the quality of the doctors who look at it.”*

Some participants also tended to rely on individual-level explanations for variations in rates of mammography. Rather than attribute differences to variations in the managed care organizations, some said things like *“When I read this and saw 30-40%, I just assumed that the rest of the people chose not to go.” “It’s a woman’s choice.”* A savvy participant responded to the latter remark: *“It’s also a cost choice – 80% in the largest plan, that’s paid for. In other insurance, it’s not covered – in some, 100% not covered at all.”* This ability to link managed care plan provisions to mammography rates was rare, however.

Overall, while participants expressed a good deal of interest in mammogram rates, for the most part they did not perceive the measures in the handbook as providing information about quality. In addition, opinions varied as to the usefulness of the information those materials did provide.

4.4 Impact and Use

Beneficiaries were asked to identify information in the handbook that they perceived to be useful. The identification of specific sections by beneficiaries helped highlight areas of information needs. Moreover, issues motivating the beneficiaries' interest in a particular section were ascertained.

While the handbook was considered to be useful for acquiring basic Medicare information for some participants, its primary use mentioned by the majority of participants in all three groups was as a reference guide. Related to the traditional sense of a reference book is a lack of perceived immediacy of the information in the Medicare handbook. Several people in the Boston group addressed the usefulness of the handbook in the future tense. *"When you go to use it, it is going to be helpful."* While the participants in Memphis and Denver spoke of the usefulness of the handbook in the present tense, the temporal use of the handbook was in part dictated by the presence or absence of personal issues beneficiaries perceived to be particularly pertinent. *"I read it only if it pertains to my problems."* Inherent in this approach is the belief that reading the entire handbook is not necessary. *"They can't design a book for everyone's individual needs, that's why they put more in here so that it applies to everyone. I don't feel I need to read the whole thing."* Instead, the strategy most commonly cited for approaching the handbook was to identify sections that fulfilled specific and personalized informational needs. *"If you have a problem, you go to the index and go right to that page and that's it. That's all you need."*

The sections that allowed for quick and easy selection of the personally relevant topics in the handbook were favored the most. The index was mentioned by several focus groups as a helpful navigational tool. It's *"like following a road map."* Another participant said *"I liked the index. It tells you where you want to go with what you want to know."* Several participants during the focus groups demonstrated the ease with which they could access information in the handbook to answer questions by using the index. The Questions and Answers were also mentioned as helpful because they highlighted important issues that could be quickly scanned and selected according to individual preference without *"having to read everything at once."* Sections that were presented in a bulleted or highlighted format, like the Q&A, reduced the extent to which beneficiaries felt overwhelmed by the textual information. One woman commented on the accessibility of the definitions, *"If I don't understand - it explains it. But reading the whole book - it's like reading a dictionary and remembering the definitions for all those words. It's overwhelming."*

Other sections that participants paid particular attention to, such as managed care information and patient's rights, were more content specific. Interest in managed care information was mentioned, as with the other sections identified above, in the context of being personally relevant. *"I'm interested in managed care because that is what I have."* In contrast, interest in information in patient rights is motivated by lack of understanding and resulting distrust of the Medicare payment system. One participant expressed his interest in knowing about his rights and protections, *"What you are entitled to. I have a suspicious nature. Who is going to pay what?"* Another participant mentioned being

interested in patient rights in the context of her knee surgery resulting in a complicated billing situation with Medicare.

Overall, personal relevance served as the primary motivator for beneficiaries' selection of particularly useful sections. As a result of the handbook being approached with the intention of fulfilling individualized needs, the actual use of the handbook varied across beneficiaries.

5.0 CONCLUSIONS AND POLICY IMPLICATIONS

Our findings suggest that beneficiaries tend to consider the Medicare program generally, and the handbook specifically, as a resource to be considered and used only in times of need. This perception influences how beneficiaries understand and use the handbook as well as other sources of information on the Medicare program. Findings are summarized in Table 2.

Access appeared to be the least problematic issue explored in the focus groups. There was an association between recalling seeing PSAs regarding the handbook and remembering receiving it, though whether this is attributable to better memories or greater awareness of public information campaigns is not clear. Most participants felt HCFA could ensure that the Handbook received attention by highlighting its role as a reference tool.

Participants suggested that one potential way HCFA could attempt to overcome the predisposition to simply storing the Handbook away unread would be to break its contents down into data that might be useful as reference material, and a short series of bulleted remarks entitled "*What You Need to Know NOW*" or similar text.

Awareness of the perceived purpose of the handbook was fairly high. Participants were less aware of the meaning of the term "Original Medicare." The focus group findings suggest that the survey results from questions using this term should be interpreted with caution, as some participants were confused by the term. They

Table 2: Summary of Findings

Research Area	Main Findings	Illustrative Quote
Access to Information	Beneficiaries had access to a variety of information sources, these include health care providers, seminars, HCFA, AARP, and HMO materials.	"Everybody is talking about Medicare now. It's a hot issue."
Original Medicare	While most participants understood the term's meaning, some felt this meant the plan was no longer available. Some participants suggested "basic" was a better term.	"I thought it was superfluous, redundant. Original from what?" "Original, means it is the first and that's what it is."
Barriers to Understanding	Perhaps one of the most significant barriers is a belief that the beneficiary already has sufficient information. It is difficult for beneficiaries to assess what they need to know, and most participants suggested they did not absorb information they weren't interested in.	"I pretty much have the information I need." "I'm not an expert but I understand it." "You're not going to go into depth unless you have health problems."
Managed Care	The participants who were not in Medicare HMOs were not interested in the material and did not learn about managed care from the handbook.	"I read the whole thing but when I got it this fall, I read the parts that applied to me. I didn't need HMOs. I didn't pay any attention to it."
Long-term Care	While aware that Medicare does not provide long term care, most participants would like to know more, and several complained that the handbook didn't adequately describe it.	"Not virtually, they cover nothing." "Medicare does not pay for long-term care."
Use of the Handbook	Focus group participants in all three cities were generally proficient at navigating the handbook to collect information and for questions that might arise	"It covers a lot of information – it points you where you need to go."

suggested alternatives like “Basic Medicare,” and many did not see a need for a modifier at all.

The handbook did heighten participants’ awareness of the availability of HCFA-sponsored information sources, though we encountered general reluctance to use the internet for information. This is in part due to lack of access to computers, and more generally to a lack of comfort with the medium.

In general participants expressed a need for multiple sources of information. They trust the general information they receive from Medicare (and from AARP), but also appreciate the more detailed information received from Medicare managed care plans, which they perceive to be accurate and customer-oriented.

Turning to understanding, gains in understanding appear to be associated with the perceived relevance of the issues being addressed. This was particularly noteworthy around the topic of managed care, with HMO members paying more attention to these materials than their fee-for-service counterparts (though we should note that knowledge gaps remained in both groups, perhaps a result of the complexity of the program). These findings suggest that it will be challenging to develop effective methods to assess the impact of the NMEP on beneficiary knowledge, as interest is an important intervening variable between exposure and gains in knowledge.

While participants were quite interested in quality of care, they did not see the measures offered in the handbook as useful indicators of quality. They recognized that

quality is difficult to measure, and varied in their interpretations of the available indicators. For example, they wondered about the source of the information on doctors who communicate well. The mammography rate was seen as a function of access to care or patient preferences. This suggests a need for more thorough explanation on both the source and the meaning of these measures.

Participants seemed most comfortable using the handbook as a reference tool. They were able to locate specific information to address each other's questions as they arose in the groups. Because informational needs varied among beneficiaries, some consensus was formed around the preferred presentation of the information in an outline or bulleted format. This structure reduced the informational burden of reading the whole text, and allowed for quick and easy identification of pertinent issues. Participant suggestions for changes to the handbook are summarized in Table 3. The variety of suggestions reflects the variety of perspectives and uses that beneficiaries bring to bear on the materials of the NMEP.

Table 3: Beneficiaries' Suggestions for the Handbook

Theme	Participant Comments
Less detail	<p>"Too much information."</p> <p>"It's got too much detail, too much information."</p>
More detail	<p>"One sentence in here: 'drugs with only a few exceptions' – can't tell from the handbook what those exceptions are."</p> <p>"There is very minimal coverage in this book on long-term care. It should be covered in more depth."</p>
Format	<p>"I would put phone numbers on the front of this, a list of numbers, like on page 23."</p> <p>"Why do I have to get all the way to page 21 before there are numbers to call for help?"</p> <p>"Break down some of the paragraphs."</p>
Helping beneficiaries remember receiving it	<p>"Put a \$50 bill in it."</p> <p>"If I paid a dollar for it."</p>
Positive attributes	<p>"I liked the index. It took me where I wanted to go."</p> <p>"One thing I noticed to be helpful was the book has 800 numbers."</p> <p>"The date on this is helpful."</p> <p>"Very good if you have a particular question and look at the index."</p> <p>"I like this book because it is large print."</p> <p>"I like the index – it tells you where to go with what you want to know."</p>

Appendix A

Final Medicare and You Beneficiary Focus Group Topic Guide

5-2-00

Introduction

Welcome. Thank you for coming to this group discussion. Your participation is very important to us and to the agency that manages Medicare.

I'm [first name] and I will be facilitating our group today. [First name] will be helping me and will be taking notes during the discussion.

We're from the Research Triangle Institute, a non-profit organization that does health-related research. The agency that manages the Medicare program asked us to conduct these groups.

Project objective:

The Medicare program is trying to learn more about what information people who have Medicare want, and what's the best way to give it to them.

Group objective:

As part of this effort, we are conducting these discussion groups with people like you who have Medicare, to learn what you know about Medicare and what you think about the materials that Medicare has developed.

Confidentiality statement:

Your participation today is voluntary and confidential. You can refuse to answer any question, and at any point you are free to stop participating. Whatever you choose to say or not say will have no effect on your health insurance. We will write a report summarizing what we hear in all the groups we do, and it will be impossible to identify any single person's comments. I would like to have an open conversation today, so that everyone is comfortable saying whatever they feel.

[If participants have not already done so, have them complete and turn in the informed consent form. Remind them that one copy is for them to keep, with phone numbers in case they have any questions or comments afterwards.]

Procedure:

- We'll be having an open conversation, so feel free to respond to me, or to others in the group, without waiting to be called on.
- We want to hear what everyone has to say, so only one person should talk at a time.
- We'll be talking for about 2 hours. There are several topics we want to cover, so I may move us along sometimes.
- I'll be using this topic guide to help make sure we cover everything we need to.
- [Explain where the bathrooms are]; feel free to excuse yourself if you need to.
- Since we won't have a break, feel free to get up and help yourself to refreshments while we talk.
- If any of my questions are unclear or confusing, let me know and I'll try to explain better.
- There are no right or wrong answers. We really want to hear from everyone. You are the experts.
- We are here to learn from you. We are not able to answer your questions about Medicare.
- Please give your frank and honest opinions. We're here to understand your perspective.

- We will be video-taping the discussion, to make it a little easier on the note-taker and for our analysis later.
1. We'll be on a first-name basis today. I'd like to start by going around the room – will each of you tell us your first name, how long you've had Medicare, and whether you have regular Medicare or a Medicare HMO? [Write 'name' and 'how long' and 'regular or HMO' on the board as reminders.]
...For those with basic Medicare, probe to see if they have any supplemental coverage.
 2. How much do you think you know about the Medicare program? *Rather than presume that self-rated knowledge is a function of need-to-know, asking this as an open-ended question allows us to get at desire to know as well as need*
...How much do you think you need to know about the Medicare program?
...Why do you think you need to know that (e.g., to be informed, to make better choices, because it's there, etc.)
 3. How much information would you say you have about your Medicare choices? *See if knowledge and understanding are based only on NMEP, or on materials from other sources, like AARP or health plan marketing materials. Also links to MCBS question on accuracy of materials, and allows us to explore preferences for accuracy versus unbiased information*
...Where do you get it?
...[If from Medicare and other sources] Is there a difference between the kinds of materials you get?
...Do you think that information about your Medicare choices would be more accurate if it came from the health plan or if it came from the Medicare program?
...Do you think that information about your Medicare choices would be more unbiased if it came from the health plan or if it came from the Medicare program?
...Which would you trust more? Which would you prefer? [Probe to get at preferences for accuracy versus unbiasedness]
 4. We sent you this recently [hold up handbook] Had you ever seen it before?
...It was sent out last fall by the Medicare program. Some people may not have received it, or may not remember it. What might help people to remember and pay attention to it?
...Do you remember seeing any newspaper articles or public service announcements before you received it?
...Okay, since you all received this recently, how much of this have you read? For those who didn't read much: it's OK that you haven't read it. We are interested in finding out why some people haven't read it. *Aim is to figure out how much people care or are interested, whether they are intimidated by either the materials or the complexity of the Medicare program, whether they take Medicare for granted, etc.*
 5. How useful was the information in the handbook? *This gets at need, again – underlying need for this kind of information, and perceived usefulness*
...Why was it useful?
...[If necessary] What did you use it for?
 6. Please turn to the table of contents. What sections did you pay particular attention to?
...Why did you pay more attention to those sections? *[due to interest, confusion about Medicare program, confusion about handbook, or what]*

7. What do you think was the main purpose of the handbook?
 ...Did it achieve this purpose? Why or why not? *Gets at overall impediments to NMEP – interest, confusion, complexity of program...*
8. You may have seen the term “Original Medicare” used in the handbook. What do you think it refers to? How do you interpret this term?
 ...[If necessary] Is this option still available?
 ...Are there other terms that might be better for talking about [that]?
 ...[If necessary] How about basic Medicare? Standard Medicare?
9. What parts of the Medicare program do you find hardest to understand?
 ...Did the handbook help you understand them any better? *Allows us to separate the effects of the handbook from the effects of the complexity of the Medicare program.*
 ...[if so] How?
 ...[if not] Why not?

[The following 7 questions highlight areas where knowledge scores were relatively low. Focus here is on understanding why gains in knowledge were relatively modest – can it be attributed to lack of interest, lack of concern, avoidance of related information, complexity of information provided, difficulty of absorbing multiple messages in a single setting, etc.]

10. How much do you know about Medicare HMOs? *Try to see if responses vary by people in HMOs versus Fee for Service.*
 ...Would you like to know more? Why/why not?
 ...Did you try to get more information about HMOs?
 ...Did the handbook help you to learn more? Why/Why not?
 ...[For people in HMOs] Do you feel like you are still in the Medicare program?
 ...[same] Does the Medicare program pay for your care in the HMO?
11. How much do you know about what Medicare covers for long-term care?
 ...Would you like to know more? Why/why not?
 ...Did you try to get more information about long-term care?
 ...Do any of you have any other insurance to cover long-term care?
 ...Did the handbook help you to learn more? Why/Why not?
 ...[If we have time] Do you know whether or not there is a limit on the number of days of nursing home care that Medicare pays for?
12. How much do you know about what's available to provide people with Medicare with help in understanding and comparing their choices?
 ...[If respondents are familiar with the resources available] Have you used them? Why or why not?
 ...[If respondents aren't familiar with resources available] Would you use the internet, a 1-800 #, the State Health Insurance Assistance Program? Why or why not?
 ...What do you think would make people more likely to use these kinds of services?
 ...[If necessary] Do you have access to the internet?
 ...Did the handbook help you to learn more? Why/Why not?
13. *How interested are you in learning about quality of care in each of your Medicare options? We found people didn't use the quality information much – this allows us to explore whether that's because they don't see the link to quality, or they are not interested in quality, or what. In addition, survey found that people who said*

they had received a lot of information on these topics scored only slightly higher on the knowledge index than people who said they'd received a little – need to explore the perceived salience and meaning of this information.

...*What kinds of information would tell you about quality?*

...Does the information in the handbook about how well doctors communicate with their patients tell you about quality? What does it tell you?

...Does the information in the handbook about how often people get tested for cancer tell you about quality? What does it tell you?

14. We said at the beginning that we are here to learn what you know about Medicare and what you think about the materials that Medicare has developed. Have we missed anything that you think we should know to achieve this objective?
15. Is there anything we did not discuss that seems important that you would like us to know?

Thanks again for all your comments on the materials. You have really helped us in thinking more about ways to meet the information needs of people who have Medicare.

Appendix B

Screening Guidelines

The ultimate goal: a representative sample of the target populations.

Target population: Medicare beneficiaries who make decisions about their Medicare coverage.

- Screen out “professional participants”
- Screen out dual eligibles (Medicare and Medicaid Beneficiaries)
- Screen out those whose original reason for Medicare eligibility was disability or ESRD
- Screen out those with vision difficulties.
- Screen out institutionalized
- Aim for mix of younger-old and older-old
- Aim for a mix of genders
- Aim for a mix of ethnicities
- Aim for mix of education levels



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